

Response to Request for information- House Public Health- Interim Charge #3

Individuals with Intellectual or Developmental Disabilities (IDD) are more likely to have a co-occurring mental health condition when compared to the general population. People with IDD are also at a higher risk of experiencing trauma such as physical, emotional and sexual abuse, neglect, bullying, and unnecessary restraints. These inherent challenges and high incidents of trauma create a unique susceptibility to the development of mental health conditions. Untreated trauma can also place children at increased risk for further developmental delay.

- Youth with IDD are three times more likely to experience trauma and abuse than their peers without disabilities.
- Approximately 30-50% of children with IDD also have a mental health condition.
- According to the May 2020 Texas Health and Human Services Report on Suicide and Suicide Prevention, the 18-24 age group identified as having a disability "were two and a half times as likely to have also had suicidal ideation." Older adults with disabilities, age 25 and older, were "more than five times as likely to have suicidal ideation."

While these numbers and risk factors speak to the desperate need for robust services and supports, access to quality treatment continues to be a problem.

Workforce

Significant workforce shortages of MH/IDD specialists, as well as limited knowledge and training for MH and IDD professionals, creates substantial barriers. Efforts to capitalize on the expertise in both fields and establish a seamless, comprehensive and integrated system of care for this population has been less than ideal. Without integrated, expert care, uninformed providers and caregivers often attribute challenging behaviors to disability and fail to adequately evaluate for underlying medical or mental health conditions. To make matters worse, overall research about people at the intersection of MH and IDD is sorely lacking. This sparse data leads to confusing or inappropriate assessments and evaluations which make the standard criteria for mental illness difficult to obtain.

Individuals and families across the state regularly report that they are unable to get the mental health services they need, and if they do, it is only in a crisis situation. Barriers include:

- The mental health provider pool for those who treat individuals with IDD is extremely limited.
- Mental health providers who do treat individuals with IDD have extensive waitlists.
- Very few providers take Medicaid
- IDD is not well-understood by mental health providers, making identification of IDD and referral to IDD services nearly impossible.

IQ Thresholds

Arbitrary IQ thresholds often prevent individuals from accessing services through public and private providers and treatment centers. Individuals with IDD and family members report being disqualified for mental health services because their IQ is not high enough. Conversely, consumers may be turned away from accessing IDD services if their IQ is too high. The absence of treatment can lead to a crisis, requiring more costly care, failure in school, job loss, and housing instability.

Agency Cross Coordination

There is a lack of fluid cross agency and department coordination as well as a lack of effective assessments and evaluations. Local mental health authorities (LMHA) and local intellectual and developmental disability authorities (LIDDA) are typically co-located, but service coordination and provision are siloed making it difficult for individuals with IDD and mental health conditions to access comprehensive services based on their level of need.

While we have seen a push to integrate other types of health services into an overall wellness framework, such as interwoven mental health and substance use care, and mental health and physical healthcare, we have yet to see this wholehearted approach concerning individuals with IDD. For instance, a consumer would not be forced to choose either to treat their depression, or to treat their diabetes because receiving services for the co-occurring conditions is not an option. Yet, this is exactly the kind of message and practice that many consumers and their families have experienced from their LMHAs and LIDDAs. Oftentimes, they are faced with the decision of which diagnosis they will treat, rather than having access to comprehensive care matched to their individual needs.

Trauma

Another important factor in providing quality treatment is understanding the significance of trauma. Attention has recently been given to the impact of trauma and the need for trauma- informed care for both child welfare/juvenile systems as well as adult criminal justice systems. The legislature has mandated trauma training in both these systems, but despite the fact that people with IDD experience high rates of trauma and institutionalization, Texas has not yet prioritized trauma-informed care for this vulnerable population.

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Recommendations

- Increase workforce capacity through training and incentives.
- Increase cross-agency collaboration to identify the mental health needs of those with IDD and take joint responsibility for meeting those needs.
- Develop systems of integrated care for people with IDD.
- Mandate trauma-informed training.
- Eliminate IQ thresholds and ensure level of need is driving treatment plans

With these recommendations MH/IDD providers will have additional knowledge and resources on how best to serve people at the intersection of MH and IDD, which will directly bolster the effectiveness of suicide prevention programming in the state. Most importantly, individuals with IDD and MH challenges will no longer be forced to choose between which condition to treat, and which to ignore, and can achieve overall wellness.